

Hello Jennifer,

I saw your recent story on the Daskalos family – about her, (Mrs. Daskalos) treatment at hospital and in particular the part of the excessive billing and tactics used by the hospital and its staff to free up beds. I became so moved by their plight I decided to write you a short letter about my own personal situation and the steps I have decided to take in order to help make things better.

Unfortunately, something similar did happen to my father and our family this past year at [REDACTED], starting in November of 2010 and ending in April of 2011. My dad suffered what many at the hospital thought was a TIA (series of mini strokes?) and was unable to remain at home safely. As a result he found himself in an acute care bed at [REDACTED]. Initially both the attention he received and the support our family received from the Hospital and its staff was actually quite excellent. Unfortunately things changed rapidly after my father had been in hospital for over 1 month with no sign of being able to return to his home anytime soon. Ultimately, after meeting with hospital social workers and CCAC representative a decision was made that my father should be placed in a long term care facility. This is where the story goes downhill rapidly. The hospital wanted us to almost immediately provide them with a list of 2-3 short-listed facilities (LTC's), as our top picks and then went on to recommended places whether we had visited them or not. Naturally our first instinct was to get defensive and insist we be given some time to explore all available avenues. Following at least a dozen visits by my brother and I to various long term care facilities, we realized that the conditions and services at these facilities differ greatly from place to place. In all honesty, some of these facilities should, at very least, be shut down temporarily in order to make repairs and much needed improvements. During our screening process it became more and more apparent that the hospital had slipped into an accelerated "eviction" mode and moreover did not appear to care that we did not have sufficient time to review all available choices properly. It was the holiday season and although I am self employed and compared to most I was able to free up many hours each day to help find a place for my Dad, it was still a very daunting task. I mean the reality is we were just expected to either take my dad to his home, which at that point everyone agreed was not an option, to our own homes which were equally ill-suited for his needs or to any available facility regardless of its condition or location in relationship to where we lived. It all came to a head when the hospital continued to insist we provide the names of our 3 short listed facilities and then they would call us in for a meeting. Of course we complied, provided our list of facilities and then promptly walked into that meeting as the proverbial "deer in the headlights". In our naivety we thought the hospital staff and the CCAC support team were going to try and work with us and help place our dad at a suitable place. Instead, we were greeted (ambushed being the better choice of word) by the hospitals "flow director" who, after exchanging some conditioned pleasantries, promptly threatened us with a \$1,600.00 a day charge if we didn't remove our dad from their hospital as quickly as possible!!

Of course we were furious and refused to be “bullied” or have some hired gun scare us into a decision. We then realized the situation had gone beyond our control and we were forced to hire a lawyer. To our surprise the lawyer provided by ACE (Advocacy Center for The Elderly) a not-for-profit legal organization, stepped to the plate immediately. Within 48 hours the hospital had been served with paper work reminding them of their legal restrictions when dealing with these situations and that they were only, by penalty of law, allowed to charge \$ 53.00 per day. As a result we were provided some much needed time for our decision making.

Ironically, during this last month of legal wrangling and meetings, my dad’s situation got slightly better. Given our available choices at the time and his improved condition we decided to have him discharged and brought home, his own home, as this is where he wanted to be all along. After seeing how much his spirits brightened when he learned the news we understood what had been forgotten in this scenario, what my dad wanted....he didn’t want to go into a LTC facility or stay in the hospital, he simply wanted to go home. When my dad was discharged around April of this year we realized that although he would be able to manage with some things at home, we were in desperate need of additional support. After a few phone calls and some careful planning, we received tremendous support by the local CCAC. Finally, we could see some light at the end of the tunnel. My dad was on a waiting list for LTC homes we were comfortable with and we thought; let’s see what happens over the next few months. We began to think, who knows if he continues to get a bit better or to stabilize we can take steps to making his stay at home as comfortable and safe as possible.

To our surprise although great for my dad’s spirit, his stay at home proved to be very challenging. My dad’s home care that was being provided by an outside agency representing CCAC was great, initially. The issue was with my dad’s home not the care being provided to him. My dad lived in an old home in downtown Toronto and as a result of his illnesses was not really able to use stairs. As well, he wasn’t able to go to the bathroom on his own as the only bathrooms in the home were either in the basement or on the second floor. To complicate matters the house had many stairs (high ceilings), narrow hallways and doorways and several other issues that made it difficult for my dad to live at home. This also made it very difficult for CCAC support staff to properly care for my father under those circumstances. At issue was the physical construction and layout of the home and its restrictions which prevented them from providing safe or adequate care. This resulted in several late night or sometimes daytime calls from my father (we provided him with an emergency call button which he wore around his neck) telling us that he had fallen (more like sat down on the steps or on the floor etc) but he was not able to lift himself. Sometime this meant that my brother or I went over to his home to help out or other times the CCAC worker arrived at the opportune time, thankfully.

This of course brought us to yet another conclusion; if he was to remain safely in his own home, regardless of his health it had to be made safe for him and for those providing his primary care. If this was not possible my father would no longer be able to remain in his own home. At that point we started looking into the basic work that would be required to make his home safe and

functional without having to gut and renovate the entire place. Being that my brother nor I are contractors, we began looking into companies that offered these services and what help we might get from our government or local organizations as he / we were on a tight budget and limited funds. I can safely tell you that after about three weeks of research we were more confused at the end than we were initially. We could not find a single organization that offered a complete service nor could we find any charitable agencies that focused on an at home living strategy. In truth, we did find a great many websites for consultants that could be hired to help you make a plan but they did not provide a build-out nor could they help with funding other than bank financing. Also, we found it very disappointing to read articles that talked about it taking over 50 steps to obtain funding from the government for something as simple as a grab bar ! Amazingly there is a great deal of publicity around an Aging At Home strategy by the government but really no plan of effective action in place.

After a few weeks at home my dad suffered another TIA or seizure and unfortunately his situation got worse, significantly worse. We came to the conclusion that living at home for him was no longer a viable option. Having used our time wisely while he was at home we were able to have him placed in an LTC that we had listed as a choice and as a result his second stay in hospital was quite brief. He is currently living comfortably in his new home and to this day insists he could be and should be at home.

The reason I decided to write you this letter is to let you know that after my initial anger and frustration subsided I was able to see the whole picture for what it was. I now understand the situation in our province when dealing with the elderly in hospitals or at home is truly unacceptable. However I recognize that people I dealt with at that time and currently are only doing their jobs and enforcing their mandates to the best of their abilities and as much as the current climate will allow. The social worker who should have been working on behalf of my father and our family was more focussed on getting us out of the hospital bed that they desperately needed rather than finding an appropriate solution. The hospital was forced to spend money on a professional “evictor” rather than investing in community outreach programs that might work in conjunction with other organizations to help find long term solutions to this overwhelming problem. This all brought me to the realization that although most people know / accept that our healthcare system is seriously flawed they have no idea how desperate the current need for at home living care has become. The simple truth is that at present hospital beds are not available for those who truly need them let alone seniors or the elderly using them for respite care. The waiting lists for solid long term care facilities can be 1-2 years if not longer. The population of seniors in our province or country for that matter is expanding yearly as we are all living longer and are leading healthier lives. The need is enormous and the resources that are now available fall woefully short. Although CCAC works with individuals and provides care for people in their own homes, this will not be enough as they cannot provide safe primary care in environments that are not suited for that purpose.

In the end I was so affected by what happened to my dad, my family and many others whose stories I have heard I felt that something needed to be done. Elders and seniors for the most part do not want to go into long term care facilities nor do they want to be in hospitals. They also want to live as independently as possible and not be a burden to family members and loved ones; they just want to live at home. In some cases, this is just not possible but in many cases with the right modifications and support, individuals can remain where they want to be ... in their own homes. The added benefit is that the space then becomes available in both hospitals and long term care facilities for those who truly need the care and the elderly who can, live longer happier lives at home.

In closing, I believe charity starts at home – and our home is Canada. Over the last 7-8 months I have formed a Canadian Registered Charity which is called The Canadian Association for at Home Aging. Our charity website is almost live, as we are just testing our various pages and establishing relationships with our industry partners. Our goal is to be able to provide funding to help the elderly and seniors, wanting to live in their own homes or that of family members, do so. This can range from those that are ill and disabled facing mobility issues and require things such as accessible bathrooms, stair lifts, chair lifts, grab bars, non-skid tiles etc., to those healthy individuals who want to continue to live at home in a safe environment. I have a lot of work to do, work that takes time and resources. To date I have personally funded this endeavour and have formed very powerful relationships with industry partners. This will allow us to roll out a charity that not only specializes in this area (no other charity currently exists, to our knowledge, with a mandate such as ours) but one that will enable us to point people in the right direction obtaining the services they desperately need. We are working with our partners to establish a “one stop” philosophy that will allow the elderly, seniors, their loved ones or care givers a complete resource encompassing all aspects of what is required to foster an At Home Aging environment. We will work hand in hand with hospitals, government, CCAC, community groups and all other related organizations to make this not only a reality but a viable long term solution. Hopefully we can create a model that others will follow and other charities such as ours will grow across Canada.

Jennifer, the reality is we need to attract a lot of attention to our cause as well as donations; private, corporate and government. Any type of spotlight you could shed on what we are doing would be greatly appreciated. Although our charity is just in its infancy, Ontario's aging population is not..... the need is in desperate, just ask anyone who's living it.

Thank you for taking the time you did to share the Daskalos family story and also to reading this letter. I fear that these types of stories will become far too common over the next few years.

Our website should be live by January 1st..

Kind regards,

Vladimir Trkulja

The Canadian Association for at Home Aging

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